

## **Virtual Mentor**

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## *Virtual Mentor*

American Medical Association Journal of Ethics  
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### **FROM THE EDITOR**

#### **Bottled 1986, Opened 2001**

Audiey Kao, MD, PhD

On a recent morning while housecleaning personal papers and memorabilia, I rediscovered something that prompted reflection on my reasons for wanting to be a doctor—my medical school application essay. On as much real estate as I could carve out of an 8 ½ by 11-inch plot, I had constructed a narrative meant to convince strangers of my genuine desire to be a doctor. I could recall experimenting with a variety of literary styles, but ultimately settling on a direct approach, putting aside penned gimmicks designed to capture the attention of admissions committees. Had the fruits of my labor aged well over time, like bottled wine? Or had the reasons for choosing medicine that I expressed more than 15 years ago turned sour? I was about to find out.

Uncorking this bottle to test the vintage gave me cause for concern. The anxiety arose in part from the fact that, over the years, I have had opportunities to critique essays from others who wanted to pursue careers in medicine. As a result, I have developed an experienced palate that I use in judging the integrity of authors' motivations as expressed in their own words. I have read few essays that fail to reflect on the applicant's idealistic reasons for desiring to be a healer. If the applicant has too romanticized a view of medicine, I question whether the idealism is frank and genuine, having met few saints in my life. If, however, I think the extreme idealism is sincere, I then worry that this individual will encounter difficult times on his or her path to becoming a doctor. Therefore, applicants who convey some personal uncertainty and anxiety about pursuing medicine may, according to my ranking scheme, actually be better prospects for medical education because they appear to be more accepting of imperfection and, thus, less prone to disillusionment. Finally, I have a jaundiced view of applicants who write about their interest in a specific specialty in medicine. Maybe it's just a pet peeve, but I simply don't think that, at that point in their lives, individuals are able to know in any informed way what kind of specialists they will want to be.

Now I was turning that critique on my expressed reasons and motivations for wanting to be a doctor. My initial read left me with less than a satisfying taste in my mouth—I violated my own pet peeve by writing about my interest in ophthalmology because I had worked in the office of such a specialist. (My history substantiates my critique—I did not go into ophthalmology.) Given my experiences in medicine since penning the essay, the primary reason that I espoused for wanting to be doctor seemed naive and simplistic—the fulfillment that comes with knowing

one is educated and equipped to help people who are sick and in need. What I did not realize then (could not have) was that what I had termed the "obligation to care" would be severely challenged during my medical education, training, and clinical practice. There are occasions now when I dread the visit of a specific patient. This professional reality can be profoundly disconcerting and seemingly contradictory to my past aspirations and motivations.

What also struck me upon further review of my essay was its simple ordinariness. My reasons for choosing medicine were not all that different from those expressed in many of the medical school application essays I have read. This narrative link, while it may reflect some practical aspect of "The Successful Medical School Application Essay," may also reveal a fundamental thread that binds all those who decide upon medicine as a career. No matter how different applicants may be, they share expectations about a physician's duties or obligations that are informed not by professional experience, but rather by how each of them wants and expects physicians to be. There will always be challenging patient-physician relationships in our professional lives. But that in no way diminishes the integrity of our motivations to enter medicine.

As we get older and, we hope, wiser, we are better able to appreciate the fullness and complexities of the earliest motivations that drew us to consider this healing profession. Therefore, uncork that personally bottled wine of yours and savor its contents—it just may be a perfect vintage.

Audiey Kao, MD, PhD is editor in chief of *Virtual Mentor*.

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## *Virtual Mentor*

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### **CASE AND COMMENTARY**

#### **Balancing Parental Wishes and Medical Judgment**

Commentary by Joal Hill, JD, MPH, PhD

#### **Case**

Jonathan Roland, an 18-month old boy diagnosed with a rare form of pediatric cancer 4 months ago, is critically ill. Initial chest surgery and chemotherapy went well, but complications developed 3 months into treatment. His parents agreed to emergency surgery, even though Jonathan was at high risk for hemorrhaging because of the medications used for his cancer treatment. This complication did occur, and Jonathan went into shock. He was placed on extra corporeal membrane oxygenation (ECMO), but has not done well. Because of swelling and infection, his surgical wound is open, and he remains at risk for bleeding, which greatly complicates routine care.

The medical staff disagrees about the propriety of placing Jonathan on ECMO, given his diagnosis of a cancer for which survival rates are very low and the risks imposed by chemotherapy drugs. One of the primary physicians asked to be removed from the case, explaining that Jonathan's care has been driven more by his father's unwavering insistence that "everything be done," than by sound medical decision making and consideration of Jonathan's best interests. Some staff share this view, and several have expressed concern that, for Jonathan, the cure is worse than the disease.

Other staff members believe that medical judgment has been responsibly exercised. A consulting oncology specialist notes that few established standards exist for treating Jonathan's rare form of cancer. Therefore, while he agrees that the prognosis looks grim, he does not believe that the decision to continue ECMO is unsupportable, particularly if the parents understand the situation and wish to proceed.

At issue today is the parents' refusal of a DNR order. A family and staff conference is called, to which the physician-chair of the pediatric ethics committee is invited. One of the physicians tells her, "We want you to convince the family to withdraw treatment, or at least agree to the DNR order."

Before the parents join the conference, members of the team—social worker, chaplains, nurses, and physicians—summarize their perspectives of the case. While everyone exercises self-control, it is evident that tensions run high, and that the morale of the entire unit is affected by the case. Disagreement continues about how

Jonathan's care should have been handled when complications first arose, but there is consensus that: (1) Jonathan's parents love their son; (2) Jonathan's prognosis is very poor; (3) His parents appear to understand the condition and outlook for their son. The team is divided about whether treatment should be withdrawn or continued, and also about whether or not Jonathan's parents should have the final say about that question.

When they join the conference, Jonathan's parents describe their son's condition accurately. They know he is likely to die, but believe it is their duty to give him every possible chance. "Even if the odds are only 1 in 10,000 or less," his father says, "We must make sure he has every opportunity. He has survived to this point. Only God knows whether he will live or die. Whether in this life or in the next life, I do not want my son to ask me, 'Daddy, why didn't you fight for me?' We cannot agree to stopping any treatment that gives him a chance of survival." One of the physicians asks, "If we exercised authority to withdraw treatment against your wishes, how would you respond?" Jonathan's father replies, "If you do everything for my son and he dies, that is the will of God. But if you do not do everything, then I would blame you for his death."

In the face of this impasse, what should the pediatric ethics committee chairman recommend? Should Jonathan's parents decide whether his treatment continues with full code status, or should the medical opinion of the physician directing Jonathan's care override their preferences?

### **Commentary**

Decisions regarding care of critically ill babies are among the most difficult deliberations in patient care. It is impossible to know what these patients would want if they could speak for themselves, and, as this case illustrates, the emotional investment of parents and medical staff is considerable. Death may be harder to accept since it cannot be seen as a "natural" end to a long life.

For Jonathan's father "doing everything" seems compatible with the sacrificial nature of parental love. On the other hand, it is Jonathan who bears the burdens of treatment, which, in view of his prognosis, members of the medical team view as disproportionate to the benefits.

Compelling reasons exist for allowing Jonathan's parents to determine his treatment, provided they have decisional capacity and are adequately informed based on sound medical judgment. It is they who are primarily responsible for their child, and who, regardless of the outcome, will live with the result for the rest of their lives. However, the considerable deference we give to parental decision making is not absolute. Certainly we would question parental decisions for this patient if they seemed primarily motivated by personal convenience, potential financial reward from his survival or death, or other factors not directly related to Jonathan's well-being.

The medical team will also live with the results of this case in the future. This includes the possibility of being blamed by family members for a patient's death. The emotional burden of such cases can be difficult for those whose life's work is giving care. Although there is no ethical distinction between appropriately withholding or withdrawing treatment, real but often unspoken feelings of defeat and abandonment often make the latter more emotionally difficult for families and physicians. The purpose of medicine is to provide treatments that are beneficial to Jonathon, not merely those that make an impact physiologically. When there is genuine uncertainty about the efficacy of a particular course of treatment, error should be on the side of preserving life. However, the fact that treatments are initiated does not mean that they can never be withdrawn.

Several factors complicate this very difficult case. The number of physicians involved in Jonathan's care make it possible that his parents received mixed signals about the purpose and efficacy of various treatments. The continued lack of consensus about how Jonathan's complications should have been treated may also indicate lack of continuity in which physician has been the primary coordinator of care and communicator with Jonathan's parents.

Certainly there is some confusion about the ethics committee chairman's role. The fact that she is a physician does not mean that she is there to help other physicians "convince the family." Rather, she should ask questions and help the team determine the range of options available to them.

Assuming that initiation of ECMO was an appropriate recommendation for this patient, it should have been made as a treatment trial to be reassessed at appropriate intervals. Recommendations should then have been made to continue or discontinue treatment with other appropriate changes in the patient's care plan. In some cases this entails transition from potentially curative treatments to those that are palliative. Judgments about the burdens and benefits of treatment are not entirely medical, since they involve perceptions and preferences around quality of life issues. However, the physician's role requires making recommendations (and providing the rationale) for particular courses of treatment, not merely presenting all "doable" options as a menu from which patients are to pick and choose. This case offers an opportunity for the care team to evaluate how it coordinates complex care in terms of which physician remains in charge of Jonathan's case and how medical recommendations are communicated to families over time. These issues are not always straightforward, particularly in teaching hospitals where staff rotation may interrupt continuity of care.

Deliberation about how to better manage such cases in the future, however, does not solve the problem of how to proceed in this case. The question to be answered is not merely whether or not to continue this therapy, but for how long and with what criteria for justifying withdrawal. If that point is reached and the parents continue to refuse, it may be necessary to initiate appointment of a guardian to represent Jonathan's interests. This would no doubt make the current impasse even

more adversarial. However, while assessment of the burdens and benefits of treatment cannot be made without regard to parental preferences, the medical team should not abdicate its role by agreeing to continue ECMO indefinitely or until the parents agree to stop.

Joal Hill, JD, MPH, PhD is director of clinical services at the Park Ridge Center for Health, Faith, and Ethics in Chicago and is completing her doctorate in medical ethics at the University of Texas Medical Branch, Institute for the Medical Humanities in Galveston.

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## *Virtual Mentor*

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### **CASE AND COMMENTARY**

#### **Oregon v. Ashcroft: Physician Assisted Suicide with Federally Controlled Substances**

Commentary by Amber Orr, JD, MPH

#### **Case**

A friend and colleague Dr. Barber was recently diagnosed with colon cancer and urgently moved from your medical center in Portland to Houston for treatment and the support of her family. Upon hearing the sad news you volunteer to help in any way and agree to accept several of her patients. Dr. Barber calls you about one of the patients you have accepted. EH, is a 46-year-old woman with liver cancer who has enjoyed a long, trusting relationship with Dr. Barber. Dr. Barber has been a strong advocate for EH and also expresses her great confidence in your professional skills and ethical wisdom. She asks you in a serious tone to complete a task that she was unable to complete before her retirement. She tells you this is very important to her, and its completion will finally allow her to focus on her family and provide significant closure to her medical career.

She asks you to write a prescription for secobarbital for EH so that EH can make a decision about her own death. Three physicians have certified in writing that EH is within 6 months of death. She has been found to be mentally competent by your former psychiatry instructor, Dr. Redman. Also in her file is a long, compelling letter written by EH detailing why she wants access to barbiturates to end her life, how she has researched her options for 3 years, and how she willingly asked Dr. Barber for a prescription.

The following Tuesday at hospital grand rounds you learn that US Attorney General John Ashcroft has issued a letter encouraging the Drug Enforcement Agency (DEA) to take action against any physician who assists in a suicide. You have taken a significant amount of time in your decision about EH and have determined that EH meets all the eligibility criteria for assistance under the Oregon Death with Dignity Act.<sup>1</sup> You also are now aware that you will be required to record your participation and the prescription of the lethal dosage of barbiturates (a federally regulated substance) with the Oregon Department of Health. Drs. Barber and Redman both remind you that your duty is to EH and that Oregon voters approved the law by 60 percent. Your trusted friends and colleagues insist that EH has the right to make difficult choices about her death, and they suggest that any alternative could be equated with abandonment of EH in her time of need.

Convinced that terminally ill adults have a right to death with dignity, yet fearful that you may lose your license to prescribe federally regulated substances, you think about the harm that such a loss would cause to you as a professional and to your patients for whom you could no longer prescribe.

### Questions for Discussion

1. Is physician-assisted suicide fundamentally incompatible with physicians' role as healers? See AMA Principles III and IV<sup>2</sup> and *Code of Medical Ethics*, Opinion 2.211, Physician-Assisted Suicide.<sup>3</sup>
2. EH's needs for powerful pain medication will become extreme as her illness progresses. Are you concerned about prescribing adequate pain medication that could result in your patient's death even where medically appropriate? <https://www.usdoj.gov/dea/pubs/pressrel/pr110601.html>. Proponents of Ashcroft's position claim that DEA agents will easily be able to determine the differences between intentionally causing a death and prescribing enough medication to provide adequate pain relief. Do you agree?
3. The legal question of authority over Oregon physicians hinges on federal versus state's rights. In 1997, the US Supreme Court ruled that the Constitution does not guarantee citizens a right to commit suicide with the aid of a physician, and it left the question of legality to state legislatures to decide. A recent US Supreme Court decision about the medical use of marijuana prompted Ashcroft's insistence that federal law regulating controlled substances be uniform throughout the United States and not be superseded by state law<sup>2</sup>. Does the memo from US Attorney General John Ashcroft to the DEA amount to government interference in the practice of medicine in Oregon? Does the memo usurp the physician's professional right and obligation to practice medicine as he or she sees fit?
4. How will the memo impact the ethical and treatment decisions you make as a professional and physician with an important clinical and ethical role in society?

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### IN THE LITERATURE

#### **Parity in Mental Health Coverage: Moral Hazard, Adverse Selection, and the Domenici/Wellstone Act**

Sam Huber

**Frank RG, Goldman HH, McGuire TG. Will parity in coverage result in better mental health care? *N Engl J Med.* 2001;345(23):1701-1704.**

A combination of economic, scientific, and social factors has resulted in disparity between private insurance coverage for mental health care and coverage for other medical care. As new facts and funding systems have taken over, political pressure to legislate against some of these disparities has come to the national attention. The Mental Health Equitable Treatment Act of 2001, sponsored by Senators Pete Domenici(R-NM) and Paul Wellstone (D-MN), has been the subject of national debate and commentary from many stakeholders in the health care enterprise. The act would expand the now expired 1996 Mental Health Parity Act to include some of the more stringent parity requirements seen in the Federal Employees Health Benefits Program and some state statutes. In a recent Sounding Board article in the *New England Journal of Medicine*, Richard Frank, Howard Goldman, and Thomas McGuire examine the historical and economic roots of mental health parity, suggesting that the Domenici/Wellstone act will improve fairness in mental health coverage but that more may remain to be done.<sup>1</sup>

The authors first trace the history of parity in mental health coverage from the 1950s to the present. They note that for many years, mental health was publicly funded, with inpatient institutions run by the state and ancillary support services coming from social welfare programs like public housing and food stamps. Private or personal insurance was more likely to cover only services for acute mental health conditions. This model was also in line with the state of treatment options and understanding of mental illness at the time. Disparity in coverage grew wider in the 1960s with the rise of indemnity insurance and competition among plans. The high cost and unpredictability of mental health services required greater cost sharing among plan members, so many plans did not cover a wide range of services.

The authors center their explanation of disparity around the concepts of moral hazard and adverse selection. The former is the tendency for increase in the use and cost of a service immediately after it becomes covered by an insurance plan. Evidence suggests that this increase is greater for mental health than for general medical services. Adverse selection refers to the fact that plans with good benefits attract individuals who know or suspect that they will need those benefits, i.e.,

people at risk for illness. A plan that offers good mental health benefits, therefore, would tend to attract patients who want to use mental health services. Adverse selection provides incentive for insurers to keep benefits to a minimum and, hence, enroll healthy people who don't expect to need expensive care.

The authors argue that moral hazard became less of an issue for health care costs with the rise of managed care. They claim that under managed care, cost is controlled at the level of physician treatment decisions rather than through patient cost-sharing or out-of-pocket expense. Since managed care does not rely on limiting patient demand for services in order to control costs, the risk of a moral hazard effect is reduced. The authors support this claim by citing data from companies that have instituted managed care for mental health and report a reduction in spending and data from states with parity laws that show spending increases of less than 1 percent of premiums. They conclude that "managed care has effectively gutted the argument that mental health parity will increase costs too much." Coupled with a recent Surgeon General's report on advances made in the understanding and treatment of many mental illnesses, Frank et al, think that parity is currently feasible.

The quest for improvements in mental health care and fairness in funding does not end with the achievement of parity. The authors argue that coverage for general medical care is lacking in its own right, so, even with parity, many services essential or beneficial to patients would remain uncovered, including case management, chronic care, and psychosocial interventions. Additionally, there are some mental health services such as behavioral therapy which do not have analogous general medical treatments and would not be covered by a parity law. The authors ask for a broader idea of health insurance, keeping in mind that adverse selection still plays a role in the development of insurance benefits. Action beyond parity is needed to improve mental health care since parity would only succeed in setting a basic level of mental health services, not in improving care to the level it should be.

Underlying the discussion of coverage for mental health services is a relationship between social stigma and parity. The Domenici/Wellstone Equitable Treatment Act would establish a floor for services similar to the floor for general medical services. The authors conclude the act "is likely to improve the efficiency and fairness of insurance coverage for mental illness." They also appear to ask for more than parity.

### **Questions for Discussion**

1. Some state statutes are explicit about which diagnoses are covered under the parity law. These tend to distinguish between "biological" disorders and others. Does such a distinction alleviate social stigma or shift it to a different subset of patients? What are the consequences of separating "biological" mental illness from "mental" mental illness?

2. The authors argue that cost sharing and coverage limits play a lesser role in cost containment within a managed care model. This leads them to write, "Managed care has effectively gutted the argument that mental health parity will increase costs too much." How do these claims map onto your experience? Do managed care companies exert more pressure at the physician decision level, as the authors claim?
3. Is legislation the only way to ensure parity? What other options might be available? Will a parity act relieve the pressure of adverse selection?
4. Is parity in insurance coverage a reasonable or beneficial goal? Will it result in improved care? The act is silent on issues of uninsured patients with mental illness, or the additional services addressed by the authors.

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1. Frank RG, Goldman HH, McGuire TG. Will parity in coverage result in better mental health care? *N Engl J Med.* 2001;345(23):1701-1704.

Sam Huber is a fellow in the AMA Ethics Standards Group.

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## ***Virtual Mentor***

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### **AMA CODE SAYS**

#### **The Use of DNA Databanks in Genomic Research**

Faith Lagay, PhD

Consideration of genetic matters has been entering the *Code of Medical Ethics* over the last 2 decades, often as add-ons or inclusions to existing opinions. In 1993, for example, Opinions 2.04 and 2.05 on artificial insemination from 10 years earlier were amended to cover newly available genetic screening to test sperm before fertilization. (Notably testing for HIV was also added to this and to other Opinions in their 1990s revisions.) Ethical policy on informed consent from research subjects applies, of course, to subjects in gene research; admonitions regarding conflict of interest in research must be heeded by those conducting genetic research, and so on. In many ways, as ethicists have stated again and again, genetic information and technology do not represent a brand new world of ethical, legal, moral, or social concerns.

On the other hand, many people insist that when it comes to issues of consent and confidentiality, genetic information *is* different.<sup>1</sup> There are 2 main reasons for thinking so. First, genetic information, and most especially DNA test results, can reveal more than an ordinary medical record; it can indicate illnesses (breast or colon cancer, for example) and risk conditions (high cholesterol, e.g.) that we might develop in the future. Such information could prejudice insurance companies and employers and could influence one's educational, reproductive, and other lifestyle decisions. The second distinct characteristic of genetic information that complicates standard consent guidelines for physicians is that data obtained about a patient may apply not only to that patient but also to other members of his or her biological family. Such information has, thus, been acquired about that family member without his or her consent and may be unknown to (and perhaps unwanted by) him or her.

For these reasons, the Council on Ethical and Judicial Affairs (CEJA) began considering genetic testing as a separate topic area for opinions and has issued opinions on genetic testing by employers (Opinion 2.132), genetic information and insurance companies (Opinion 2.135), ethical issues in carrier screening (Opinion 2.137), genetic testing of children (Opinion 2.138), and multiplex genetic testing (Opinion 2.139).

At its winter meeting in 1999, CEJA was asked to investigate and report on how physicians should deal with the increasingly thorny issues surrounding test results. Should they document test requests in regular patient records? Should they document test results? If test results affect a patient's family member, what should physicians

do? How should they respond to the rapidly expanding demands from the judicial system for DNA information to be used in adoption and custody cases or for forensic use in criminal cases? CEJA subdivided this large cluster of questions twice, setting the justice issues apart for separate consideration and then subdividing the remaining non-justice-related issues into (1) those issues that concern individual patients and (2) those that concern the special area of population genetics. This subcategory—gene research on populations, called "genomic" research—is the subject of Opinion 2.079.

Genomic research is not clinical research; that is, it does not concern itself with attempts to diagnose or treat illness in individuals. Rather, genomic research looks at specific loci on the genome and notes the similarities and differences at those loci among many people. These horizontal studies reveal that many different forms of a gene (polymorphisms) exist at a given locus; some polymorphisms affect an individual's health or appearance and some do not. Understandably, genomic studies yield more information when conducted among people about whom medical history and family history are available—populations of people, in other words, who are stable, remain in the same place over generations, and marry people on whom medical histories and records are also available. For these reasons, genomic researchers find studies of American Indians, groups such as the Amish, and those who have remained in a distinct geographic location (like the residents of Iceland) particularly attractive. But studying a group that identifies itself or is identified by others as distinct on the basis of its heritage, culture, beliefs, or geographic confines presents consent and confidentiality problems that transcend those found in clinical gene research with individual subjects.

CEJA approached these challenges with greatest concern for protection of informed consent. Because study results will be made public, all group members will have information about aggregate data that may or may not apply to them as individuals and that they may or may not have sought on their own. There is, on average, about 0.1 percent difference between the genomes of any 2 randomly selected individuals; roughly 40 or so of the approximately 40,000 genes scientists currently think *Homo sapiens* possess. But, and here a second risk to consent comes in, as genomic research is attempting to clarify, genes act in conjunction with each other and also with the environment and other lifestyle influences, so that groups that have shared environment, diet, and other customs over many generations and have married others like themselves, may have slightly more genetic similarity than the general 99.9 percent of the world population. And they may have medical histories that show even greater similarities in illness patterns. Having enough subjects to be able to find correlation between genes and health factors is the beauty of population genetics, but it opens the possibility of discrimination or stigmatization of all members of a group on the basis of generalized studies in which individual members did not consent to participate.

Finally, DNA databanks can preserve genetic material so that it can be used over and over again for research purposes through time, and CEJA was aware that, because of



this, subjects who consented to participate in one research protocol might be unwittingly committing their DNA samples to later research projects that they had not consented to and, perhaps, would not approve of.

With these special sensitivities in mind, CEJA determined that policy regarding genomic research must consider both (1) some procedure for consulting the whole group and (2) stringent consent procedures for individuals who chose to participate in the study. The recommendations adopted at the House of Delegates meeting in December 2001 that became Opinion 2.079 laid out these guidelines.

### **Regarding the group being studied**

". . . investigators should consult with the community to design a study that will minimize harm not only for individual subjects, but also for the community. *When substantial opposition to the research is expressed within the community, investigators should not conduct the study.* When the community supports a proposal, investigators nevertheless should obtain individual consent in the usual manner. The same procedure should be followed whether the investigators intend to collect new samples and data or whether they wish to use previously archived data sets."

### **Regarding the individuals who consent to participate**

1. Standard informed consent principles apply. In addition, the specific standards of privacy operating in the study must be disclosed. Will the material be "coded (i.e., encrypted so that only the investigator can trace materials back to specific individuals) or . . . completely de-identified (i.e., stripped of identifiers)"?
2. "If data are to be coded, subjects should be told whether they can expect to be contacted in the future to share in findings or to consider participating in additional research."
3. "Individuals should always be free to refuse the use of their biological materials in research, without penalty."
4. "Disclosure should include information about whether investigators or subjects stand to gain financially from research findings."
5. "Subjects should be informed of when, if ever, and how archived information and samples will be discarded."

Finally, Opinion 2.079 advises that "to protect subsets of the population from such harms as stigmatization and discrimination, demographic information not required for the study's purposes should be coded."

The *Code of Medical Ethics'* new Opinion on use of DNA databanks in genomic research takes a strict line on informed consent by groups and individuals who are

subjects of such research. Some procedure for securing group consent must be designed and implemented with the group and individuals must give consent to both the initial and any subsequent use of their genetic material..

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Faith Lagay, PhD is managing editor of *Virtual Mentor*.

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## *Virtual Mentor*

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### **MEDICINE AND SOCIETY**

#### **Triage and Ethics**

Ken Kipnis, PhD

The term "triage" refers to the procedures clinicians use to prioritize prospective patients. In the background is the unhappy truth that, when vital resources are limited, some will not get what they need, at least not right away. One branch of the field of bioethics deals with the broad problem of allocating scarce medical resources. That discussion, in turn, has its roots in what has long been the central topic of social philosophy: the idea of distributive justice. In the emergency department, patients are usually queued in accordance with the easily grasped principle that the more urgent the complaint, the shorter the wait to see a doctor. Those with the greatest need get priority. As clear and as fair as the rule is, people still complain about the wait.

Analytically, one can think about the patients who present at any clinic as constituting a stream of discrete health-related problems, each of which requires an assessment and an appropriate medical response. The burden to the clinic will be a function of 3 factors. First, there is the rate of presentation of the prospective patients. Other things being equal, more patients per hour means more work to do. Second, there are the resources that are needed to assess and stabilize each patient and to treat his or her condition. While many medical problems are easily diagnosed and treated, others can become burdensome responsibilities. Finally, there is the acuity of each patient's condition. How long can we postpone treatment before the delay aggravates the medical problem and creates a greater need for care? Taken together, these 3 factors delimit the burden of patient need. Though hospitals and other institutions have the responsibility to shoulder that burden as it appears, their carrying capacity can be overwhelmed.

Sometimes—several times a month in many hospitals—a surge of patients or a shortage of staff temporarily overloads carrying capacity. On these occasions, there may be an acknowledgement that the staff's resources are inadequate to provide appropriate and timely treatment for the stream of prospective patients. Rather than offering substandard care, medical centers will go to "bypass," closing their doors to new patients and diverting ambulances to other hospitals. Here, carrying capacity is conceived as regional: institutions have an ethical obligation to work cooperatively to meet the needs of the communities they serve.

Hospitals have to use a different strategy for disasters: train wrecks, plane crashes, earthquakes, tsunamis, and so on. When mass casualties overwhelm the everyday

queuing procedures in all regional centers, diversion fails. This second line of defense has its origins in 19th-century military medicine. Because the goal of war is victory (rather than saving lives), French doctors learned to give priority to injured soldiers—especially officers—who could readily return to the fray. Unlike everyday clinical triage, those with the most serious wounds would receive treatment on a delayed basis, if at all.

Today, disaster triage uses tagging systems that are intended to sort out (1) those who will probably die even if treated, (2) those who will probably live even if not treated and (3) those who will probably live if treated but die if they are not. Those in the third category get priority, especially if their medical conditions are emergent and the procedures required to stabilize the patient are relatively simple. Because errors at intake can create serious problems downstream, this procedure works well only if experienced clinicians handle the initial assessments. Queue-jumping is permitted only if it will return caregivers to their posts during the course of the disaster, increasing the supply of health-related resources during the period of scarcity.

Though it can strain everyday moral sensibilities that the most seriously injured will be set aside to die, there are powerful ethical arguments in support of this hard-headed approach. In the first place, it produces the best outcome; certainly if clinicians have a paramount duty to prevent the largest number of deaths, this is the way to do it. Second, if it were clear that a catastrophe would occur but unclear how serious one's own injuries might be, rational persons would do well to choose this procedure just because it gives them the best chance of survival. Finally, it can fall to clinicians to be stewards of critical and scarce resources during these crises. The primary obligation of stewardship is to prevent waste. Disaster triage provides a kind of guarantee that critical resources will be used with maximum efficiency, that waste will be kept to a minimum. To their credit, hospitals in the United States regularly conduct disaster drills and are generally prepared to handle the tornadoes and train wrecks that would otherwise overwhelm local medical systems.

Though the paragraphs above represent a quick survey of a well-established area of medicine, the threat of terrorism has generated a new need to consider a third line of defense. We can think of a medical catastrophe as a large-scale disaster where the burden of patient need overwhelms the carrying capacity of a regional or national system. Though the Tokyo Sarin gas attack was a comparatively small event, within 60 minutes hundreds of victims arrived on foot at a nearby hospital. Though only 12 died, 5000 poured into emergency departments, contaminating hospital areas and sickening health care personnel. The more serious release of methyl isocyanate in Bhopal killed thousands and injured hundreds of thousands.

In a catastrophe, hospital clinicians would be unable to assess all those presenting for medical care, unable to monitor those for whom treatment has been delayed, and unable to provide follow-up care for those who have been temporarily stabilized. As the injured deteriorate without treatment, more resources will be required

because of delay. Even when the goal is to evacuate the injured to neighboring regions, that too requires assessment, stabilization and care. It can happen that exhaustion and competing responsibilities will draw caregivers away from their posts and that those waiting for desperately needed treatment will not appreciate why it is unavailable. Finally, crowds, contamination, cross-infection and damaged infrastructure can compromise health care facilities themselves. In the worst case, the National Guard would have to protect medical centers from angry, sickening mobs, driven perhaps by a suspicion that essential resources are being hoarded. Hospitals may themselves become serious health hazards.

There are, I believe, 2 important lessons to be taken from such scenarios. First, hospitals cannot manage triage during catastrophe. At some point, disaster triage will be overwhelmed. And second, when catastrophe looms, hospitals must close their doors well before they reach disaster-level capacity, relocating their resources and diverting prospective patients to pre-designated peripheral healthcare venues.

It may be useful to begin to think of pharmacies, neighborhood clinics, hotels, high school gyms (with showers for decontamination), and fire stations (with EMTs) as emergency sites. The aim in a catastrophe is to reduce travel and concentrations of people. We should follow the Israeli model and teach citizens to shelter-in-place, preparing sealed rooms for riding out the crisis. Health care personnel—including dentists, veterinarians, nurses, retired medics, volunteers, etc.—should know when to move to pre-assigned locations. Plans should exist to stock those venues with supplies. Hospitals should be prepared to become coordination centers with robust communication links to peripheral sites. If they need care, citizens should know it is available around the corner and that hospitals are to be avoided.

In learning to manage crowded emergency departments and disasters, physicians have supplemented their traditional patient-centered focus with strategies intended to meet the needs of groups. As worthy as progress has been, the medical profession has not yet outgrown the obligation to stretch its capabilities.

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## *Virtual Mentor*

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### **PERSONAL NARRATIVE**

#### **Post 9-11 in Kenya**

Robert Davidson, MD, MPH

On September 11, 2001, the world changed. The terrorism tragedies at the World Trade Center and the Pentagon have affected every American in some way. I thought you would be interested to hear how it has impacted my work and Americans living in eastern Africa.

I was working in Malawi on September 11. We first heard the news when the information officer at the American Embassy in Lilongwe called over to the Peace Corps to inform them of the terrorist attacks. I am sure most Americans in the US turned to their television and followed the tragedy live. No television was available at the Peace Corps office, but we were able to get the BBC on short wave radio. It seemed surreal to be sitting in a small office listening to a British newscaster describe what was going on in New York and Washington. Rumors began flying. The first was that the US Air Force was going to shoot down commercial airplanes that were veering off course. The US Embassies in eastern Africa were placed on high security alert. Memories of the embassy bombings in Nairobi and Dar es Saalam were still fresh in many peoples' minds.

Back in my hotel room, I was able to get the BBC television channel and watch the incredible videos of planes flying into the World Trade Center. I sat there with tears in my eyes and a mixture of sadness and anger. I wanted to be with people, so I walked down to the lobby. An obvious African Muslim man looked at me and smiled. He said, "I guess the US is finally getting a taste of what the Palestinians have been getting." In the bar were a group of Americans sitting in a corner. I did not know any of them and usually would have avoided them, thinking we probably had little in common but our citizenship. They were ex-military contractors working on a project at the US Embassy. They were loud, cigar-smoking, beer-drinking Texans who fit the stereotype of the Ugly American. However, they *were* American, and I needed to be with some countrymen. I could take only about an hour of their increasingly hostile attitude that "we should "bomb the \*\*\*\* out of whomever did it." I could, however, identify with their anger and need for the US to do something.

Over the ensuing 3 months, the aftermath of the attack has continued to affect us on a daily basis. A number of the volunteers were frantic with worry about friends or family in the New York area. The usually unreliable Kenyan telephone system was completely overloaded. All we could get was the recorded message in Kiswahili

that "all lines are busy, please try again later." Then we began getting families, and even a couple of congressional offices, calling to find out when we were sending the volunteers home. There was no terrorism in Kenya, and the volunteers were probably safer at their sites than they would be trying to fly back home. This would be impossible for a few days anyway, since all flights to the US were cancelled. Things slowly returned to a relative calm until the 2 follow-up events occurred that affected us more than the initial attack. The first of these was the anthrax mailings, and the second was the US attack on the Taliban in Afghanistan. Because humor is important in these times, I want to relate a few of the anthrax stories in Kenya.

By way of background, anthrax is naturally occurring and quite common in eastern Africa. The Masai herds of cattle are universally infected with it, and spores are everywhere in the soil. It is not uncommon to get cutaneous anthrax infections that respond nicely to doxycycline. One of the volunteers was diagnosed with cutaneous anthrax by a local physician and started on antibiotics. She happened to mention to her parents in a weekly e-mail that she was being treated for anthrax with no other explanation. That prompted a panic call from the parents to the Peace Corps headquarters in Washington asking what the hell was going on. The headquarters' staff gave the parents my phone number, and, of course, the inevitable call came at 3:00 a.m. "Was their daughter being flown out in an Air Force medical evacuation plane? Was I a real doctor? CNN should know that Peace Corps volunteers are being attacked by bioterrorists." When I was finally able to explain what was going on, her parents seemed skeptical but at least somewhat reassured. The next day I developed an information sheet on anthrax and sent it to all the volunteers so that we could avoid similar situations with their families.

Several days later, I got a call from an obviously distraught volunteer teacher who said her headmaster was demanding that all the teachers in the school be flown to Nairobi for examination and given prophylactic antibiotics against anthrax. The headmaster's demand was precipitated by a package my caller had received. She had sent to the Planned Parenthood Association in the US for some brochures on HIV/AIDS prevention that she planned to incorporate in her teachings. The brochures arrived in an envelope. She opened the package while sitting in the teachers' lounge. As she tore open the envelope, the gray/brown powdery insulation spilled out onto the table causing a panic among the teachers, who ran to the headmaster's office yelling, "Anthrax, anthrax." I was able to assure the headmaster that there was no risk of anthrax. I did ask her to put the package in a plastic bag and send it to me in Nairobi where I would have it tested. I never heard from her again. However, the next day I got a call from a family doctor colleague from the US who was working in Kenya at a mission hospital. There was a group of students from a church school in the US who were in Kenya for a bible study program at a mission school. The bishop in the US called the mission hospital in Kenya to demand that all the students be placed on Ciprofloxacin as prophylaxis against anthrax. My colleague had tried unsuccessfully to calm the bishop. He needed, he said, "some muscle from the US Government." I was able to help him by contacting

a CDC research physician working in Kenya whose advice, I guess, had enough "muscle."

The War on Terrorism has had a more sinister effect in eastern Africa. Both Kenya and Tanzania have huge Islamic populations, some of whom are fundamentalists very close in ideology to the Taliban brand of Islam. As much as we say that the US attacks are not attacks on the Islamic faith, they are perceived as just that—attacks on Islam. There have been several anti-US demonstrations with the ritualistic US flag burning in major cities. The real effects on volunteers are subtler. Americans who board a *matatu*, a Nissan bus that is the local mode of public transportation, are told, "Watch out. Bin Laden is sitting in the back seat." Popular beach resort areas have been declared "off limits" because they are predominately Islamic and have sub-groups suspected of being allied with the terrorist network. All in all, America's War on Terrorism makes an already stressful job that much more difficult.

It is sad that the world must go through this destructive phase. Most eastern Africans, including most members of the Islamic faith, endorse US actions. I understand the need for closing down the terrorist threat to the US and the world. I only hope we will be equally committed to rebuilding and supporting the countries we attack. I also hope the world can understand that we attack terrorism by fostering the development of Third World countries in a more lasting way than bombing them.

My best wishes to all of you for a peaceful 2002.

Daktari Bob  
Area Peace Corps Medical Officer for Eastern Africa.

Robert Davidson, MD, MPH is professor in the Department of Family and Community Medicine at University of California, Davis, where his interests include both rural health and the organization and financing of health care systems. In the past few years, he has served as both the director of Rural Health and earlier as the medical director of Managed Care for the UC Davis Health System. *Out of Africa* is an on-line journal of his odyssey in the US Peace Corps as the area Medical Officer in Eastern Africa.

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## *Virtual Mentor*

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### PERSONAL NARRATIVE

#### **Fred**

F.R. Burdette

I first saw the notice for hospice volunteer training about the time I retired—about the time I started giving more thought to my own longevity. I had already signed my Living Will and Durable Power of Attorney for Healthcare. The idea of hospice care as an alternative to being hooked up to a machine appealed to me. Although I wasn't sure what was expected of a hospice volunteer, it seemed like a worthwhile undertaking.

I had retired from substance abuse counseling which had been rewarding for the deep connections I often established with clients. Working with people who knew they were dying seemed to offer at least as much potential for such connections. But, this was not a decision I would make lightly despite the immediate appeal; I tore out the notice and filed it away in a folder of possibilities for part time employment or volunteer work.

I saw additional notices for hospice volunteer training from time to time, but it was never convenient to attend. When I did have more free time, I only thought about it on weekends or after hours.

The day didn't come until 3 years later that I called the hospice team office to inquire about training. A new series of training sessions was set to begin in a couple weeks. I signed up. I had an initial feeling of exhilaration; I couldn't wait for the training sessions to start.

By the time the training started, I was beginning to doubt my qualifications, but the more I learned about hospice, and the more people in the organization I met, the more I knew it was right for me. I felt like I was entering an exciting new phase of my life. Then I couldn't wait to be assigned my first patient.

When the call came the exhilaration returned, followed by my doubts as I prepared to telephone and arrange my first visit. After all, who was I to present myself to some poor dying soul and his grieving family? What did I have to offer? The volunteer coordinator mentioned the patient enjoyed playing dominoes; I didn't even do that.

I'll call my patient Fred not because that was his name but because it wasn't; hospice patients' identities are confidential. He did remind me of a Fred that I had

known a long time before but even revealing the reasons for that would tend to compromise his identity.

Although Fred's wife was not a hospice patient, she also required twenty-four hour care. Their daughter lived nearby but was employed full time, and I was unable to contact her that day. I made arrangements with the evening attendant to visit on Saturday morning hoping the daughter might also show up.

The son-in-law came to the door Saturday morning and I went into the family room to meet Fred, his wife, their daughter, and the Saturday attendant. At this point I violated my first hospice rule by forgetting to wash my hands on arrival. Fred sat on the sofa—eyes closed, not speaking. I talked briefly to the family. The daughter told me, "He was alert and playing dominoes a couple days ago but he's just sleeping now." I went over to him and tried unsuccessfully to introduce myself. How can I relate to someone who doesn't talk? I admitted that I had just completed my volunteer training and that Fred was my first patient. The family had questions for me. I responded with more questions. Hospice volunteers don't give advice. We engaged in awkward small talk until I excused myself saying that I would come back a couple times the next week and see if Fred was willing and able to talk with me then. This wasn't exactly what I had hoped it would be like. I bought some dominoes and arranged to have a friend teach me how to play. I only wanted to play well enough not to aggravate Fred. I figured he'd enjoy beating me; I knew my friend would.

Tuesday morning Fred was more alert; his medication had been adjusted. He responded to my questions about what kind of work he had done, how long he'd been married, how many children they'd had, and that sort of thing. Although his answers weren't always accurate, it was still some kind of communication. He asked a few questions too. Was I a doctor? A nurse? He told me I could come back and take over at 4 that afternoon when everybody else was gone—which they wouldn't be. I told him I would bring dominoes the next time I came. It was still not what I was looking for, but I had made a little progress. At least, I felt like I had introduced myself, and I was more comfortable with the smaller audience.

I called Thursday morning to see if that would be a good day to visit. The attendant told me he'd been angry. I told her I wasn't afraid of his anger. I'd done some of my best counseling work with angry people. I was excited that he was angry and hoped it would be a way for us to start talking. Forget dominoes.

By now, Fred was in a hospital bed in the family room and the sides were up. His wrists were bandaged where he had tried to cut them. He tried to talk a little but was incoherent. The only thing I understood was when he yelled, "Pull me up!" once when he was choking. Still I had the sense that he knew who I was. Later he reached for my hand and I held his for about 20 minutes without speaking until he fell asleep. I could hear the rattle in his chest. I found myself praying for him to die, then retracting the prayer both because I don't believe in praying for God's direct

intervention and when Fred would die wasn't really a volunteer's business no matter what I thought or felt. There must be a hospice rule about that.

I planned to visit Monday but before I did, I got word from hospice that Fred had died Friday. I was glad for him. I figured he had been ready when he tried to cut his wrists and that at last his suffering was over. I was glad for him but I felt empty.

I decided I'd go to his funeral, but he had already been buried early Monday morning. The next best thing would be to visit with his daughter or the daytime attendant who I imagined would still be there with Fred's widow. I had had more contact with the daytime attendant. I had only met her twice but she had been helpful and friendly both times and I knew she'd cared about Fred. Her shift ended at 3, so I waited until Tuesday to go by the house. When I did, the garage door was down and the van wasn't in the driveway anymore. The house looked different; *it* looked empty. I drove on.

F.R. Burdette lives, writes, and walks the seawall in Galveston, an island off Texas, in the Gulf of Mexico.

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## *Virtual Mentor*

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### VIEWPOINT

#### **If Laughter Is the Best Medicine, Who Is Scrubs Healing?**

Sam Huber

From *Marcus Welby, MD* to *ER*, medicine has been a mainstay of popular television drama. Generally, doctor stories on TV have resulted in good PR for the profession: the hard-working physician facing life, death, and personal drama strives to maintain individual and professional integrity every week for 60 minutes. Recently, comedy writers have turned to medicine for material. While *MASH* was a humorous critique of war, the new NBC show *Scrubs* turns to lampooning the medical profession itself.

Beyond its shortcomings as an unsubtle workplace comedy relying on internal monologue in the *Ally McBeal* mold (a device also found in *Working*, *Inside Schwartz*, *Titus*, and the upcoming *Imagine That*), *Scrubs* plays an interesting role in airing medicine's jokes and dirty laundry in public. Many of the jokes told in recent episodes are caricatures and observations students and physicians will recognize from in-house spoofs and class plays. Who hasn't worked with or couldn't recognize an overconfident and crass attending, a jaded and bigoted chief, a procedure-happy surgeon, a gunner, or a naïve misfit? These hollow, hyperbolic characters and stereotypes populate our internal jokes and self-spoofs, and *Scrubs* contribution to popular understanding of American medicine may end there.

Granted, the reputation of American medicine is not on the line Tuesdays at 9:30/8:30 central, nor should it be artificially protected from criticism by humor writers or anyone else. Yet, like reading an unauthorized biography, it is somewhat compelling to see what dust gets swept under which rug. Reality/anthropology TV notwithstanding, we can learn a lot about a group of people by looking at what jokes they tell about themselves. Perhaps that is what the writers of *Scrubs*, slotted between *Frasier* and *Dateline*, are intending.

Classical comedy, like its tragic counterpart, seeks to illuminate certain truths about humanity. Through buffoons, victims, characters we are meant to wish well, and those designed for our spite, we come to understand a little more about the human condition and ourselves. So if "*Scrubs*" accomplishes anything more than entertaining, it might be affording us a look at the human troubles and humor of coping with a first job out of school, in this case medical school, although the added years of schooling count for little, given the delayed adolescence of the main character, Dr. Dorian (J.D.), and his surgeon friend, Dr. Cox. For the show to succeed on network television, it must appeal to a broad audience, to "everyman,"

and many folks in new, confusing situations can see something of themselves in J.D.'s reactions and internal monologues.

*Scrubs* is not a very effective tool for teaching medical ethics—NBC's ad for one episode promises "J.D. (Zach Braff) is enchanted by an unseen female patient (guest star Elizabeth Bogush, 'Titans') who is trapped inside an MRI machine—and even considers asking her out." But it could help on the professional development front. Much has been written popularly about humor as a coping mechanism, and that may apply to students watching "*Scrubs*." There is camaraderie in a joke you can recognize in your own life, and in shared experience. Although "*Scrubs*" may be neither a documentary on the life of an intern nor a weekly dramatization of professional dilemmas, it does serve to show how bad (and funny) things can be. Perhaps medical students and interns will find their own difficulties with adjustment to a new or confusing situation normalized through humor.

Will patients act differently toward their physicians for having seen *Scrubs*? Probably neither more nor less than they would after watching *ER*. Perhaps one can triangulate a more realistic picture of American medicine through *ER* and *Scrubs* together as different kinds of exaggeration.

It is always beneficial to be able to laugh at oneself. To invite network television viewers to laugh along probably doesn't hurt either. There is plenty that isn't funny about contemporary medicine, so having a laugh at the system's expense is probably good medicine for all of us.

Sam Huber is a research assistant in the AMA Ethics Standards Group.

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